Excluded by Design: Epistemic Injustice in Dementia Diagnostic Standards

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Abstract

Dementia affects millions of people worldwide. Migrant communities are at increased risk of dementia while simultaneously experiencing inequity in diagnoses. This article argues that contemporary dementia diagnostic standards systematically exclude the cognitive experiences of the global majority, rendering migrants epistemically invisible within clinical systems calibrated to Western populations. Diagnostic justice warrants the development of inclusive diagnostic standards, ancestry-diverse biological research, and equitable global research collaborations.

Keywords: Dementia, Diagnostic Testing, Epistemic Injustice, Diagnostic Testing

Introduction

Dementia affects over 55 million people worldwide, yet there are global disparities in diagnostic distribution.[1] Despite being more vulnerable to dementia, migrants in high-income countries are more often misdiagnosed, diagnosed late, or undiagnosed, especially if they are of African or Asian origin.[2] These disparities are frequently attributed to cultural distance, language barriers, or individual clinician limitations.[3] While these factors affect clinical practices, they fail to

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[2] Selten, J. P., Termorshuizen, F., van Sonsbeek, M., Bogers, J., & Schmand, B. (2021). Migration and dementia: a meta-analysis of epidemiological studies in Europe. *Psychological medicine*, *51*(11), 1838–1845. https://doi.org/10.1017/S0033291720000586

[3] Hurley S, Turnbull S, Calia C. Barriers and facilitators to diagnosing dementia in migrant populations: a systematic review of European health professionals' perspectives. *Int J Geriatr Psychiatry*. (2024) https://doi.org/10.1002/gps.6118; Leroi, I., Vaitheswaran, S., Sheikh, S., Chaudhry, N., Goswami, S. P., Miah, J., Sakel, M., Tofique, S., Husain, N., & SENSE-Cog Asia Collaboration (2020). Capacity & capability building for applied dementia research in low- & middle-income countries: Two exemplars from South Asia. *The Indian journal of medical research*, *152*(6), 614–625. https://doi.org/10.4103/ijmr.IJMR_2095_19; Sagbakken, M.,

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explain why diagnostic failure is so systematic, persistent, and institutionally reproduced. This paper argues that inequities in dementia diagnostics among migrant populations reflect not a failure of cultural competence but an ethical failure of knowledge production. These inequities stem from epistemic injustice embedded in global research structures that determine whose cognitive experiences generate the evidence used to define dementia. By examining how global research inequities shape diagnostic tools, clinical encounters, and institutional responsibility, I contend that achieving diagnostic justice requires epistemic repair at a global scale.

Dementia Underdiagnosis in Migrant Populations Is Not Accidental

While low- and middle-income countries (LMICs) account for an estimated two-thirds of the global dementia population,[4] this distribution reflects their large share of the world's population rather than a higher age-adjusted prevalence. The key disparity lies in diagnostic capacity: despite bearing the majority of cases, LMICs possess only a fraction of the diagnostic infrastructure available in high-income countries (HICs), resulting in formal diagnosis rates below 10 percent in many LMICs[5] compared to approximately 50 percent in high-income regions.[6] For migrants, this structural gap creates a distinct paradox: individuals of African and Asian origin in HICs face significantly elevated dementia risk — particularly vascular dementia — yet they remain systematically underdiagnosed. They have a higher prevalence of vascular comorbidities, as well as higher rates of social isolation and lower educational attainment. While care-seeking norms vary, reluctance to pursue diagnosis cannot explain why, when migrants do present for care, diagnostic tools fail to validly capture cognitive impairment.[7] This paradox emerges because migrants come from systems where dementia is rarely diagnosed and find themselves in health systems whose tools are not calibrated to their linguistic, educational, or epidemiological backgrounds, effectively ensuring that their heightened objective risk remains clinically invisible.[8]

Spilker, R. S., & Nielsen, T. R. (2018). Dementia and immigrant groups: a qualitative study of challenges related to identifying, assessing, and diagnosing dementia. *BMC health services research*, *18*(1), 910. https://doi.org/10.1186/s12913-018-3720-7

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Standard reform efforts typically emphasize "cultural competence" as a silver bullet for these gaps. While this approach is valuable, it does not explain persistent disparities seen across clinicians and institutions. Attributing underdiagnosis of migrants to clinician training, individual bias, or a lack of cultural competence obscures a more structural cause: the diagnostic tools and evidentiary standards used in the consulting room are derived from a research ecosystem that excludes much of the global majority.[9]

Epistemic Injustice in Dementia Diagnosis

The persistent underdiagnosis of dementia in migrant populations is a form of epistemic injustice. It occurs when clinicians exclude patients as credible sources or conveyors of knowledge within clinical systems. In dementia care, this exclusion operates through two mechanisms. First, migrants experience testimonial injustice when clinicians discount or misclassify their narratives of cognitive change. This often arises from intersecting biases, including ageism and assumptions about how cognitive decline presents in culturally diverse populations, leading clinicians to attribute reported symptoms to "normal aging" or psychosocial factors rather than initiating formal evaluation. As a result, patient-reported concerns are deprioritized, delaying or preventing diagnostic workup. Second, migrant populations face interpretive injustice due to a collective gap in interpretive resources. Because standard diagnostic tools were not designed to accommodate the linguistic, cultural, or educational backgrounds of many people from LMICs, clinicians lack adequate interpretive frameworks to evaluate cognitive symptoms when they are expressed.[10] Consequently, diagnostic systems fail to register migrant patients' experiences as clinically meaningful.

How Global Research Inequity Produces Diagnostic Harm

A global research monoculture has produced the downstream diagnostic harm that migrants experience. Approximately 90 percent of all dementia studies rely on high-income populations in the US and Europe, despite these regions representing only 10 to 15 percent of the global population.[11] This imbalance narrows the "standard" of cognitive health to a specific demographic: Western, English-speaking, and relatively highly educated.[12]

Hurley S, Turnbull S, Calia C. Barriers and facilitators to diagnosing dementia in migrant populations: a systematic review of European health professionals' perspectives. *Int J Geriatr Psychiatry*. (2024). https://doi.org/10.1002/gps.6118

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Examples of this research inequity appear in widely used cognitive tests, including the Mini-Mental State Examination (MMSE) and the Montreal Cognitive Assessment (MoCA). Researchers standardized these tests using Western cohorts, introducing biases in education, literacy, and test design.[13] Individuals in rural schools in LMICs or unfamiliar with standardized testing formats may score lower due to test design rather than cognitive impairment. Such miscalibrated tools produce dual harm: false positives and false negatives. False positives pathologize cultural and educational differences. False negatives delay recognition of true impairment when clinicians, wary of test bias, misattribute genuine decline to "normal aging" or cultural variation, thereby increasing the risk of misdiagnosis.[14]

Biomarkers and genomic risk factors, such as the APOE-ε4 allele, are validated primarily in European-ancestry populations, even though the association between these markers and dementia risk varies meaningfully across genetic ancestries.[15] Furthermore, interpreter-mediated assessments using standard tools can lead to severe distortion, as even professional translators often unknowingly alter the core meaning of cognitive items or provide cues that compromise the test's validity. Finally, the lack of clinical standards for bilingualism and late-life language attrition leads clinicians to mislabel complex linguistic patterns as pathology.[16] In India, for example, 22 official languages and hundreds of dialects complicate the development of a single standardized cognitive battery. Similar gaps exist across Africa and Southeast Asia.[17] National health systems in many LMICs rely on diagnostic tools developed and standardized in high-income countries, which often fail to reflect local sociocultural contexts or educational distributions. At the same time, migrants in HICs are assessed using the same instruments, despite their misalignment with patients' backgrounds, reinforcing a form of structural dependence on Western-derived standards.

Migrants enter HIC health systems without the valid reference standards necessary for accurate diagnosis. Existing diagnostic norms do not account for their linguistic, educational, and cultural heterogeneity, leading systems to

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misinterpret differences as pathology. Underdiagnosis in some populations also reinforces a self-perpetuating feedback loop: communities excluded from diagnosis remain underrepresented in research, ensuring that the evidentiary gaps driving diagnostic failure persist over time. When the entire scientific foundation of dementia diagnosis — from cognitive batteries to PET-imaging thresholds —relies on data obtained in HICs, diagnostic inequity becomes a predictable outcome.[18]

Over time, these diagnostic failures produce downstream harms that extend beyond clinical delay. Both overdiagnosis and underdiagnosis — arising from the same epistemically miscalibrated tools — distort access to care. Misclassification may either restrict access to appropriate treatment or inappropriately medicalize individuals whose cognitive differences reflect education, language, or culture rather than pathology. These errors increase caregiver burden, limit patient autonomy, and affect eligibility for disability benefits, immigration proceedings, and social services, further amplifying existing structural vulnerabilities.[19]

Ethical Responsibility and Institutional Obligation

The systematic underdiagnosis and misclassification of dementia in migrants is not a failure of individual clinical cultural competence.[20] While clinicians bear responsibility for individual encounters, they often operate with low confidence and insecurity because they use structurally inadequate tools. This uncertainty leads clinicians to delay referrals, avoid complex assessments, or defer diagnosis until symptoms become severe.[21] Instead, the ethical responsibility lies with research institutions, global health funders, and international collaborations that generate and legitimate diagnostic standards.[22]

The failure of institutions to correct these inequities perpetuates an ongoing harm against vulnerable populations. When institutions and NIH-equivalents continue to fund and rely on research in which people of European ancestry are overrepresented, they exhibit an institutional form of ignorance that systematically limits who can be recognized

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as a legitimate clinical subject.[23] Therefore, epistemic repair must be viewed as a fundamental institutional duty, rather than a charitable endeavor.

What Diagnostic Justice Requires

Achieving diagnostic justice imposes three concrete institutional obligations. First, institutions must undertake epistemic repair by developing and implementing multilingual, education-stratified diagnostic tools. Instruments like the Rowland Universal Dementia Assessment Scale (RUDAS) and the Cross-Cultural Dementia Screening (CCD) perform well across diverse linguistic and educational backgrounds. Yet they remain underused because they lack large-scale validation, integration into guideline frameworks, and reimbursement support. These tools must be scaled and embedded into national clinical guidelines to ensure the diagnostic process is not a privilege of the highly educated.[24] Critically, this repair is not merely about increasing diagnostic volume but ensuring accuracy. Some tests yield false-positive rates as high as 42 percent in non-impaired minority groups, and false negatives delay recognition of true impairment.[25] By embedding these tools into guidelines, institutions ensure that the diagnostic process is a reliable resource for the global majority.

Second, institutions must ensure epistemic inclusion in biological diagnostics. Biomarker research and genomic risk models, including those involving the APOE-ε4 allele, cannot remain ancestry-neutral when the association between these markers and dementia varies meaningfully across genetic ancestries. Expanding ancestry-diverse biobanks is a scientific necessity to prevent the reproduction of molecular inequities. While some may argue that these disparities could be addressed through improved cultural competency among clinicians, such a framing is insufficient; no amount of individual skill can rectify a research enterprise that systematically excludes the global majority from its foundational evidentiary standards.

Finally, institutions have an obligation to epistemic sovereignty, requiring a shift away from extractive research practices toward equitable international collaborations. Collaborations should support local LMIC leadership and promote sustainable capacity building to ensure that the normative data generated in countries of origin provides the essential reference standards for accurate diagnosis across settings. Addressing the concern that diagnosis leads to unwanted medicalization, diagnostic justice recognizes that while many families prefer home-based care and view facilities as a last resort, a valid diagnosis remains a prerequisite for autonomy. Accurate knowledge of a condition allows individuals and their families to make informed financial, legal, and care decisions within their preferred cultural frameworks, rather than being thrust into medicalized care after years of diagnostic neglect.[26]

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Conclusion

Framing the systematic underdiagnosis of dementia in migrant populations as an unfortunate by-product of cultural distance or clinical uncertainty obscures a more disturbing reality: diagnostic inequity reflects a global research ecosystem that defines cognitive normalcy using evidence drawn from a narrow segment of humanity. When migrants encounter diagnostic systems that are calibrated to highly educated, monolingual standards, they are rendered invisible and suffer harm that far exceeds mere clinical delay. This harm represents a deep form of epistemic injustice rooted not in individual clinicians but in institutional decisions about whose cognitive experience defines universal diagnostic standards. Ethical responsibility for these systematic failures thus extends beyond the consulting room to the research institutions and global funders that legitimate and disseminate exclusionary diagnostic schema. Achieving global diagnostic justice requires adopting epistemic repair, including the structural integration of culturally anchored cognitive models and ancestry-diverse biological research. The legitimacy of dementia diagnosis in an increasingly migratory world depends not on individual competence but on whether the evidentiary base of clinical practice reflects the full diversity of human cognition.